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ABSTRACT

Mental health professionals and parents of children and adolescents with serious mental health problems from four contiguous "frontier" counties participated in two separate focus groups about service delivery issues. The four counties met the frontier criterion of low population density, had high poverty rates, and were federally-designated health professional shortage areas. Service providers cited three related problems as most significant: lack of transportation, long waiting lists, and "desperately underserved" kids. Providers listed eight mental health problems of children and adolescents and discussed the extreme shortages of trained staff, alternative sources of care, the role of school counselors, and the high cost of psychotropic medications. Ethnic and cultural differences among the counties resulted in lack of acceptance of service providers in some areas. Providers offered 31 suggestions for improving service delivery. Parents emphasized problems of money, geography, and lack of high-quality services. Some parents voiced anger toward the system, while others were satisfied, citing counseling and medication as most helpful. Parents in more remote areas were most dissatisfied; psychiatrists were a particular target of their anger. While parents and providers agreed on a substantial number of problems, they differed on issues of provider-client communication in ways that suggested a lack of a "shared assumptive world." (SV)

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Letter to the Field No. 17

Sheila Cooper and Morton O. Wagenfeld

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Delivering Mental Health Services to Children and Adolescents with Serious Mental Illness in Frontier Areas: Parent and Provider Views

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by Sheila Cooper and Morton O. Wagenfeld Table of Contents

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Introduction

Adolescents and children are our link to the future, so attending to their health and mental health needs is a vital investment and should be accorded a high priority. A previous *Letter* (No. 16) described some of the models of service delivery to this group in sparsely-populated frontier areas — a historically-underserved group living in a special and unique part of the United States. Some of these approaches were adaptations of urban or more populous rural models; others were developed specifically for frontier areas. This Letter builds on the earlier one by providing input from both service providers and parents of children with serious mental disorders—those closest to the problem.

There are 394 frontier counties (equal to or less than six persons/square mile) in 27 states. These areas are at the extreme end of a rural/urban continuum. As a group, frontier America constitutes less than one percent of the population, but forty-five percent of the land mass. While the frontier of historic imagination no longer exists, it does live on, protected from large-scale settlement by harsh climate, difficult terrain, lack of water, distance from metropolitan areas, lack of exploitable resources, and federal land policies. These areas contain a high proportion of persons living in poverty, and have a limited local tax base. Federal and state programs provide most human services. Low population densities make it impractical to deliver labor- and resource-intensive programs. In addition, of course, there is the chronic problem of hiring and retaining a qualified staff.

A Snapshot of the Focus Group Site

The Frontier Mental Health Services Resource Network invited mental health professionals and parents of children and adolescents receiving care for mental health problems from four contiguous frontier counties to participate in two separate focus groups. Although each of the counties met the frontier criterion of low population density, their diversity was profound. Two of the counties are among the least populous in the state or nation, with 1990 population densities of 0.4 and 1.7 persons per square mile. The only community mental health center is located in the community where the focus group was held (which we will refer to as *Central Place*). The service area for the community mental health center totals 19,783 square miles, making transportation and driving distances a major issue for both professionals and clients. One of the counties—which has a geographic area of 6,928 square miles—is larger than the states of Delaware and Rhode Island combined. All four counties are quite impoverished; the percentage of families below the federally designated poverty level ranged from 18% to 25%. Per capita income in these counties was below state and national levels. Federal lands constituted as much as 63% of the land area of one of the counties and 50% of another. Major industries vary from mining to ranching.

The four counties are all federally-designated health professional shortage areas. The only psychiatrist is located in the same county as the community mental health center. There is no in-patient psychiatric care for children and adolescents in these counties. The nearest such facility is 115 miles from the Central Place and much further for most of the service area. Only one county has a public sector primary care provider. In 1995, the most recent data available, suicide rates for all age groups in two of the counties exceeded the state average of 2.4 deaths per 100. The national prevalence figure is 1.3. From 1993 to 1995 the average suicide rates per 100,000 population in this state for males age 15-24 was 37.7; the

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national rate was 23.4. For females in this age group the national and state suicide rates were 3.7 and 7.3, respectively. The effects of distance, poverty, underfunding and lack of services are likely reflected in these figures. Births to teen single mothers did not exceed the state average in any of the studied counties, but the state rate exceeds the national figure.

Providers And Parents

The groups were held on a Saturday at a local university. To encourage open discussion, two separate sessions were held; one for providers and another for parents. Each group lasted for about two hours. The sessions were audio-taped, and major points put on a flip chart. A set of questions was prepared in advance and individual questions are included below in italics. The format of this *Letter* is to aggregate the responses to the questions. In some instances, side comments did not easily fit into a question, but are included wherever possible.

Providers. The providers in this group were from the mental health agency that served the four-county catchment area (CA). Most of them were enthusiastic participants and, at times, it was difficult to keep up with the flow of responses. The agency has 1.5 FTE psychiatrists. A little over 6 therapists serve the two major population centers. The caseload for the case managers was 25 - 30; for the more intensive program Assertive Community Treatment (ACT) it was 12. For a few families, the modality was intensive home-based care.

> *What is the first thing that comes to mind when I mention mental health services for children and adolescents in frontier areas?*

They cited three related problems as most significant: lack of transportation, long waiting lists, and—as one staffer put it—"the kids were desperately underserved." In situations where there is conflict in the biological family or the parents are unable or unwilling to care for the child, foster care is frequently employed. Not enough foster parents were available in the area. There were no mental health inpatient services for children and adolescents within a reasonable distance. From some parts of the CA, it was necessary to drive over 150 miles to receive this service. In addition to distance, the roads were typical of frontier areas in this part of the country: narrow and mountainous.

> *In your opinion, what do you think are the major mental health problems for children and adolescents in this area?*

The participants listed eight mental health problems:

- substance abuse
- suicide
- child abuse
- incest (particularly in two counties)
- depression
- domestic violence
- homelessness
- developmental disabilities

Several side comments dealt with shortages. It is well known that rural areas suffer from extreme shortages of health and human services. Problems in frontier areas are even more extreme. Staff —often with less than optimal levels of education—need to travel long distances to reach clients. One clinician summed it up well by noting: "We're it!." In addition, they felt their salaries were much lower than in other areas. One participant noted, "I could make double what I make here. But why? I don't want to. I like it here."

> *If a young person has an emotional problem around here, how does one go about getting help? To whom do you turn? (Probe for "formal" and "informal" caregivers: e.g., specialty sector, primary care sector, ministers, public health nurses, county agents, family, neighbors, etc. In areas with large Hispanic or Native-American populations, probe specifically for alternative healers (e.g., Curanderas, shamans)).*

One could receive help directly through: walk-ins at the clinic, making an appointment, calling a

24-hour crisis 800-number, or from a mobile crisis unit. Adults, but not children, can go to the emergency room at the local hospital. In addition to direct client contacts, they received a large number of referrals from a variety of sources: members of the clergy, shelters, school counselors, and primary care physicians. Indeed, the latter group was the major source of referrals.

Participants volunteered a number of responses for alternative sources of care:

- ministers and churches
- primary care physicians
- family and neighbors. (The group felt that this was a particularly important resource and that people were deeply involved.)
- these providers referred clients to curanderas when appropriate. (One therapist noted that these healers "...help them (patients) help themselves.")
- public health nurses
- child protective services
- juvenile probation
- domestic violence shelter
- jail
- peer support programs (includes mentoring, mediation, and teen court)
- Big Brother/Big Sister
- private therapists who deal in alternative or complementary approaches (e.g., Reiki massage therapy, Healing Touch)

Particular mention needs to be made of school counselors. They are an obvious source of case-finding and first-line treatment. In general, feeling toward them was positive, particularly in view of the fact that they were overwhelmed; one district did not even have any. The linkage was essentially one-way: referrals to the mental health center for drug and alcohol screenings. As one participant noted: "They look to us for resources. We're their resource, they're not our resource. They're the one who send us the clients, but they're not a resource. We don't refer back ..... to [them]."

The providers did not see the state hospital—seven hours away—as accessible or helpful since it does not provide care for children and adolescents. Finally, it is worth noting that one important source of care that was mentioned as being absent in the area was detoxification. The nearest service was about 115 miles from Central Place.

A related issue in resources is the availability of psychotropic medications. These drugs often spell the difference between remaining in the community or being hospitalized. Because of widespread poverty and the lack of health insurance, obtaining these medications is quite difficult. The mental health center will provide one year of medications while the client qualifies for benefits. Another source of these drugs is donations from pharmaceutical companies.

> *How well do agency staff understand the particular emotional problems of young people around here?*

As we noted in the section on the demographics of the CA, the four counties are dissimilar in their ethnicity, culture and values. This creates problems for providers. They noted the difficulty in being accepted by clients, along with the statement, "They want us when they need us." It's interesting that staff felt the lack of acceptance was most evident in the least populous and most remote counties. Staff felt that more bilingual therapists were needed, but that cultural competency was not a problem. They noted that the staff is half Hispanic and half Anglo, just as the counties themselves are. In addition all of the employees have participated in workshops on multiculturalism and many have taken a multiculturalism counseling class at a local, small public university.

> *A major health care issue nationally is managed care. By that, I mean organizations like HMOs that attempt to control utilization and cost of health and mental health services. Has it had any impact in this area?*

Responses to this question were, in general, a mixture of frustration and anger. One respondent referred to it as "mangled care." Some jokes were made about managed care (MC) and one respondent said that they laughed so that they wouldn't cry.

A Medicaid MC was introduced in one county and was scheduled to be instituted in the other three in early summer, 1998. The center was part of a Behavioral Health Organization of 12 members. Among the problems cited were:

- less money
- increased bureaucracy
- confusing and contradictory requirements
- mandating intake assessments in what they consider to be an unreasonably short time
- unethical nature of MC — making large profits at the expense of client services
- poorer quality of care for persons with a serious mental disorders

To elaborate on some of these points, there was a great deal of discussion about alleged cost savings. When the state was directly funding services, the center could expect to spend about 80% on clients. With the introduction of an additional echelon, the amount available has declined to 50 or 60%. As a consequence, one therapist noted that clients were "deeply suffering." The limitation on number of visits goes against the chronic nature of schizophrenia, bipolar disorder, borderline personality disorder, and major depression with psychotic features. While patients need intensive care at the beginning of treatment, once stabilized, they could be seen monthly.

> *Let's say that we could put together, from the ground up, a mental health program for an area like this. The program would be designed to serve all persons in need of services. What would be the ideal program for you?*

Not surprisingly, there were plenty of responses to this question. The providers offered 31 suggestions on various aspects of an ideal system. Eliminating redundancy, they were:

- funding for expansion of services and for increased staff and staff salaries
- a nicer facility
- day care for both clients and staff
- a housing assistance program
- employment services
- detoxification services
- a training center
- inpatient facilities for children and adolescents
- safe home for teenagers
- group homes
- better transportation
- centralized computers with links to the Internet
- less paperwork, standardized forms
- improved communications system
- increased client accessibility
- family-based system
- more wilderness or experiential programs
- sex education for clients
- a system to assist teenagers become used to the "real world" through part-time jobs, job skills training
- preventive services
- skills-based education (parenting, goal setting, anger management, job preparation, problem solving)
- a focus on substance abuse prevention

Parents. The participants in the group were a mixture of one-and two-parent households, both Anglo and Hispanic. Their children had a number of serious mental disorders.

What is the first thing that comes to mind when I mention mental health services for children and adolescents in frontier areas?

Here, the participants volunteered a variety of answers, stressing problems of money, geography, and access to and quality of services:

- having to drive so far
- trouble with agencies
- suicidal children
- agencies are hard to deal with
- anger at the lack of agency responsiveness. One parent asked plaintively: "Why wasn't there help?"
- a lack of money to pay for services
- a too-easy willingness of providers to hospitalize their children without finding out the nature of the problem
- confidentiality was a major concern. Too many persons with no need to know were privy to the problems of the children.
- labeling. Related to confidentiality, parents expressed concern that their other children, as well as they, would be stigmatized and isolated, making the situation worse.
- lack of understanding by the community
- a need for family advocacy
- lack of communication between clinicians and parents. It was often seen as difficult for parents to understand what was wrong with their child. Information came out in bits and pieces, but they [parents] were required to act, even with incomplete knowledge.
- an over-reliance on pharmacology, often given at inappropriate doses and a lack of supportive services to help the children understand the nature of their problems
- the need for individualized treatment
- long distances to hospitalization that were financially draining
- a generalized and diffuse view that no help was available
- the need for more staff to serve outlying areas

If a young person has an emotional problem around here, how does one go about getting help? Who do you turn to?

The parents listed the following options:

- Make a lot of long-distance calls.
- Mental health center
- Pediatrician
- Primary care physician (This was qualified by the feeling that the physicians were not familiar with the full range of psychotropic medications.)
- Clergy

Although not a direct response to the question, they continued to voice anger toward the system: for example, "I can't get help," "Nobody cares," "They just say it, but it's not there." Long waiting lists were also cited.

How helpful are all these mental health services? Are people satisfied? Which would you rate most helpful? The least?

For some of the participants, response to the question on satisfaction was short and emphatic: "Zero." Others—mainly residing in or near Central City—expressed more satisfaction. It is interesting that the most vocally negative were from one of the more remote counties. The residents of this county were also those the staff saw as least accepting of services.

Participants cited two services as most helpful: counseling and medication. They further noted that more dependable and reliable choices were needed in counseling. Counseling services needed to be "sensitive" and "good." Additional concerns were: lack of transportation and insurance coverage.

How well do agency staff understand the particular emotional problems of young people around here?

Although we did not ask this question specifically, the answers to some of the other questions displayed a pervasive feeling of dissatisfaction. Again, those living in the more remote areas were more vocal about staff's lack of understanding. A particular target of ire were psychiatrists. They were viewed as thinking that they knew the problems of the child better than the parents. Additionally, parents felt that they had to implement treatment plans that they did not fully understand and that the doctors would unilaterally change medications or put the child on a vacation from the medications.

Let's say that we could put together, from the ground up, a mental health program for an area like this. The program would be designed to serve all persons in need of services. What would be the ideal program for you?

We were surprised at the flurry of responses to this question. They very eloquently listed over 16 suggestions:

- affordable
- dependable
- reliable
- 800-number
- people who care, listen, and try to help, not thinking that they know more than you do
- affordable medications
- knowledgeable people
- transportation
- reasonable distance to affordable services
- more trained and educated people
- preventive services
- public education about mental illness to avoid stigmatization
- extended peer and parent support groups to enhance coping skills
- an outdoor weekend for parents and children
- educational material about day-to-day coping with the problems of living with a child with a mental disorder.
- public policy to encourage more mental health professionals to work in frontier areas (This was starred on the chart!)

Providers and Parents: Convergence and Divergence. It is appropriate to end this *Letter* by noting points of agreement and disagreement between the two groups. While the parents and providers expressed problems in different terms, it is also clear that both were in agreement on a substantial number of points. They include geographic barriers, deficiencies in services, pressing need for services, long waiting lists, need for more staff, and advanced training for staff.

The areas in which parents and providers disagreed were what one might broadly term "communication." The literature on client/provider differences as an impediment to the effective delivery of mental health services is voluminous (e.g., Frank & Frank, 1991; Snowden, 1982; Wagenfeld & Wagenfeld, 1981). Differences in the tendency to define a problem in mental health terms, in willingness to seek help, and in expectations of outcome have been shown to be influenced by socioeconomic status, gender, race, and ethnicity. In their classic work, Frank and Frank (1991) said that a *shared assumptive world* was necessary for therapeutic success.

In response to the question of how well agency staff understand the emotional problems of young people, providers commented on the difficulty of being accepted by clients, along with an assertion that the clients wanted help in a selective way. While acknowledging the need for more bilingual therapists,

they did not feel that cultural competency was a problem. The parents, on the other hand, expressed strong negative feelings towards the providers. They said they wanted knowledgeable people who care, listen, and try to help, without thinking that they know more than you do. This discrepancy in viewpoints may be the result of the lack of a shared assumptive world as described by Frank and Frank. Much work remains to be done to reduce this barrier to access.

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